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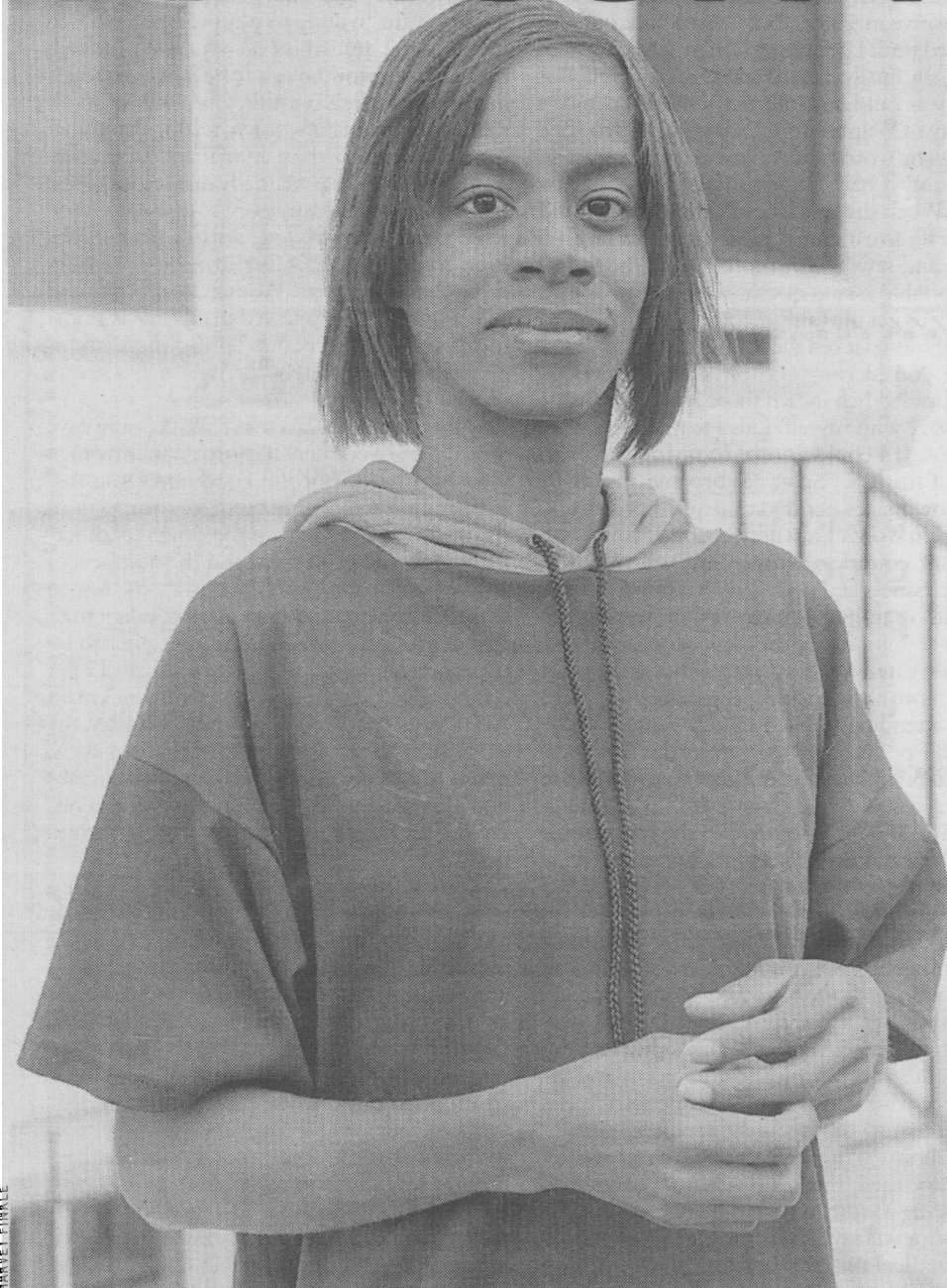
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DYING OF CURIOSITY



Jeannine Scott's doctor would see her for only five minutes: "I felt helpless, very helpless."

AIDS DEATHS ARE DOWN AMONG MEN, BUT UP AMONG WOMEN

BY MARK SCHOOFS

PASADENA—The best news of the AIDS epidemic emerged this year: For the first time, American AIDS deaths declined. But not for women. According to the Centers for Disease Control, mortality fell by 15 per cent among men, but among women deaths rose by 3 per cent.

This statistic reverberated throughout the four-day National Conference on Women & HIV last week in Pasadena, which drew 1500 doctors, researchers, and advocates. "I had no idea how far behind we were," said New York activist Michelle Lopez, one of more than 400 women with HIV who attended the gathering. Indeed, just before the conference opened, the CDC reported that AIDS has advanced from the fourth to the third leading cause of death for women in their prime, 25 to 44 years old. For African American women of that age, AIDS is the number one killer. And women are the fastest-growing group with the disease, now accounting for a full fifth of the nation's caseload.

Why are deaths among women continuing to rise, even as new therapies offer unprece-

dented hope? Research shows that women tend to get diagnosed later than men, and are more likely to receive substandard therapy and to be caught in the cycle of poverty and its attendant ills. But the life stories of HIV-positive women—many of whom were attending their first AIDS conference—made these statistics come alive.

Jeannine M. Scott found out she was HIV-positive in 1989, “but I went back out and used until I got into rehab in 1993.” At that point, she finally tried to take care of herself. But there was only one infectious-disease clinic in her city of Wilmington, Delaware, and to see a doctor she would always have to wait at least an hour and a half. Sometimes she would just leave. When she stuck it out, “the doctor would see me for five minutes. He’d weigh me, take my vitals, and say, ‘Here’s more AZT.’ I didn’t feel comfortable asking questions, ‘cause he was in a hurry to get me out.”

She also lacked the confidence to ask questions, considering her physician “someone above me.” When she left those appointments, “I felt angry with myself. I also felt helpless, very helpless. If I couldn’t turn to my doctor, who could I turn to?” Scott has become an activist and now makes her doctor explain everything to her “in words I can understand.”

But countless women are still mired in powerlessness and poor care. A study from Los Angeles examined which women were given protease inhibitors, the new wonder drugs. Women cared for at private clinics were eight times more likely to have gotten the drugs than those attending public facilities—but a whopping 85 per cent of women in the study depended on public care. Another study looked at women who were not taking AZT. The drug is so well known it is featured in the lyrics of the Broadway musical *Rent*, but 12 per cent of the women were not taking AZT because they had never heard of it.

Poor men with HIV face many of the same burdens, but even among African American men, who are often severely disadvantaged, deaths ebbed last year by 4 per cent. Many doctors still assume AIDS is a man’s disease, says Alexandra Levine, a leading clinician and researcher who cochaired the conference. “If a man comes to the emergency room complaining of shortness of breath, the health-care worker will immediately think, ‘HIV-related pneumonia.’ But seeing a woman with the same symptoms, the doctor will say, ‘It’s the flu.’” Beyond poverty and medical preconceptions, there are also “different life realities for men and women,” says Levine. Many women with HIV suffer from domestic violence—several studies found that half had been abused—and women are more much more likely than men to be caring for children.

Scott has three children, and she used to “take care of them before I would take care of myself. I would only go to the doctor if I had a cold past two weeks. I wouldn’t take time to make an appointment just to check up on my health.” Lopez, who has an HIV-positive daughter, says, “Women don’t have health care, we only have sick care.”

There may be purely biological reasons why women’s death rates continue to climb. HIV acts differently in women and men, with each gender more prone to certain diseases and cancers. But, with few exceptions, these distinctions are poorly understood. Some studies have found women to be more susceptible to wasting, bacterial pneumonia, and, most alarming, death. But none of these studies is definitive. “That’s the issue,” said Levine. “We don’t have the data because the studies haven’t been done.”

Many doctors believe the biggest difference between men and women lies in their reaction to medicines. It is well known that sex hormones, such as estrogen, affect how the

body absorbs drugs. But for years, women of childbearing age—which means virtually all women with HIV—were excluded from most clinical trials. (In at least one case, women who wanted to participate were required to undergo sterilization.) The justification was to protect the fetus, should a woman happen to get pregnant. But activist Maxine Wolfe debunked this rationale. In a plenary address that received a standing ovation, she pointed out that scientists are “willing to put pregnant women in perinatal transmission studies.” Indeed, there are currently plans for 13 new mother-infant transmission studies, involving more than 4000 pregnant women, testing drugs that have all been shown in animal and laboratory experiments to be potentially dangerous to the fetus or mother. Moreover, Wolfe said, men have never been excluded from drug trials, even though birth defects can be caused by drug-damaged sperm. Women, said Wolfe and other speakers, are viewed primarily as transmitters of HIV to babies and to men, not as people who desperately need research and care in their own right.

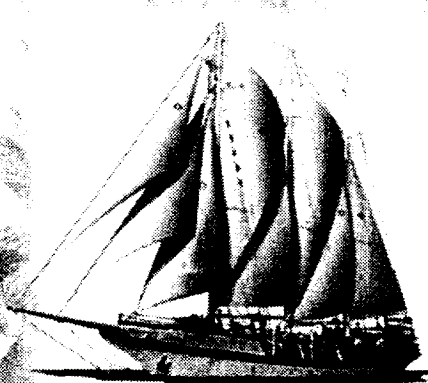
Lawsuits and years of activist pressure have forced the government to slowly admit women into drug trials. But the Food and Drug Administration still does not require an analysis of the results to determine if the drugs act differently in women and men, and the numbers of female participants are almost always too low to make valid scientific judgments. Excluding trials that examine transmission from mother to fetus, women have accounted for less than 12 per cent of all participants in the government’s main AIDS-drug trial group. In private industry, the situation appears even worse. Women comprised only 8 per cent of the main trial for Abbott’s protease inhibitor ritonavir, and a minuscule 3 per cent of the trial for Agouron’s nelfinavir.

At the conference, one of the few drug trials with a substantial proportion of women found an important difference: Between doses of the medication delavirdine, twice as much drug was found in the bloodstream of women than men. Luckily, women did not suffer more side effects, but that may be because the drug is not very toxic in general. With protease inhibitors, which often cause severe reactions, many doctors said they were seeing more side effects in women than men. Conference attendee Barbara Embree said she is “crippled with pain during my menstrual cycle,” due to a three-drug regimen that includes a protease inhibitor. “Even if a woman had all the money in the world and [top AIDS researcher] David Ho was her doctor,” said activist Mary Lucey, “she still wouldn’t know what drugs to take.”

The same social forces that push women into substandard research and care also keep them from mobilizing politically. Gay men have economic clout, most don’t have to spend time and energy raising kids, and their husbands don’t beat them up if they suggest using a condom. As a result, gay men have built a critical mass of activist muscle and scientific expertise. What was clear at the conference is that, 16 years after the first woman was diagnosed with AIDS, women are still building that critical mass. “Some medical terms go over my head,” said Bernadette Twyne Dasher, who has had AIDS for 12 years but, because of addiction and poverty, has been an activist for only seven months. “I wrote down a couple of things—those that I could spell—and when I get home I can look in my HIV dictionary and talk with my doctor.”

These problems are hardly new—indeed, they long predate AIDS. So, especially for veteran activists, the conference was tinged with frustration. “I hear us swarming with all this angry energy,” said advocate Dawn Averitt. “It’s like someone’s revving an engine in neutral, and I just want to scream, ‘Use the clutch! Put it in gear!’”

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